# Patient access to psychiatric records: the patients' view

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## Summary
The passing of legislation relating to subject access to personal health data has been accompanied by concern about the possible harmful effects of this development on patients. Despite the lack of substantive evidence psychiatric patients have been regarded as the group most at risk. This study investigates the subjective views of patients on access to records on two psychiatric wards.

## Introduction
The Data Protection Act (1984) grants access by individuals to personal information stored on computer databases although the right of access has now been modified such that data can be withheld if it is deemed 'likely to cause serious harm to the physical or mental health of the data subject'[1]. At the present time the vast majority of medical recording is done manually but computerized methods are likely to become increasingly common in the future. Several writers have speculated on the desirability or otherwise of patient access to medical notes with much discussion of ethical and practical difficulties, but there has been strikingly little evaluative research in this area.

Gillon has outlined three arguments in what he terms 'the case for deception'[2]. Firstly, that the information could be harmful to the patient, secondly, that it is impossible to tell the patient the truth (due to the elusive nature of that concept) and thirdly, that patients prefer to remain in ignorance. It is the first of these points that has been highlighted as especially pertinent to psychiatric patients. Gevers writes 'inspection of the record by the patient himself would not always serve his best interests since his health and welfare might be prejudiced by sudden confrontation with the truth, particularly in cases of terminal and mental illness'[3]. The DHSS consultation document on subject access stated that it may be especially relevant in some cases of psychiatric illness for the patient 'not to learn fully of the nature of his illness'[4]. This view has been echoed by several other authors[5-8]. Indeed, a recent editorial in this journal went so far as to suggest that in terms of the suitability of records for patient consumption, psychiatry forms the least acceptable end of a spectrum of all specialties with obstetrics at the other[9]. Yet it is particularly in psychiatry that patient involvement in the planning and implementation of a treatment programme is essential for ensuring its acceptability and success and where fostering an understanding of problem behaviour and illness processes forms an intrinsic part of treatment. In addition, issues of civil liberties are of relevance in psychiatry and for some years it has been common practice for detained patients to be afforded the opportunity to read detailed reports prepared for Mental Health Review Tribunals.

Few studies have addressed the issue of case note access specifically in psychiatric patients. In one American study voluntary inpatients on a psychiatric ward were given their records to read each evening for a period of 5 months[10]. Nursing staff were available to assist in explanation. The patients' reactions were largely positive and the majority of staff considered the new policy to form a 'useful therapeutic tool' and commented on the improved quality of the notes. In another American study 7 psychiatric patients, all of whom had been discharged from hospital and had made repeated requests for access, were allowed to read their notes[11]. The study's tentative conclusion was that these patients did not appear to be harmed in any way and many viewed the experience as positive.

In one of the few British studies Bird and Walji described open access in a general practice setting[12]. The severely disturbed patient (defined as 'so unwell psychologically that any information may exacerbate the illness') was one of the rare categories where access was withheld, but this did not apply to all cases of mental illness. A second general practice study found that although patients with psychiatric problems were likely to become upset about particular issues on reading the notes, the patients considered record sharing to be 'reassuring, informative and helpful'[13].

It may be that the paucity of British studies on psychiatric populations is related to the fact that few psychiatric units operate a policy of open access to records. It thus seemed opportune to explore the matter further by conducting a study on a ward where open access to current records formed part of normal clinical practice.

## Aims and method
The aims of the study were firstly to ascertain the extent of awareness of patients as to the existence and availability of the medical records. Secondly, to ascertain if patients wished to have access and the type of information they would like to have made available. Thirdly, to conduct a preliminary exploration of the patients' views of the subjective effects of access. A questionnaire which sought to obtain the patients' views in these areas was administered by personal interview by two of us (PB & JP). Part of the questionnaire was a modified version of that used by Stein *et al.*[10].

Thirty patients were on a ward where they had access to a file containing day-to-day records of all disciplines made during that particular admission. This information was made available on a daily basis

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and formed a focus of discussion between the patient and the nurse keyworker. In addition, patients on this ward were specifically asked if they would like to read medical, psychological and social reports prepared for particular purposes such as Mental Health Review Tribunals or the Courts. Previous notes were not generally made available although reports contained references to past medical assessments. The other 30 patients were on a ward where the notes were not routinely available.

## Results

Sixty out of 62 patients approached agreed to take part in the study. One patient failed to complete the questionnaire as his ability to concentrate was impaired. All the patients on the 'access ward' were aware that notes were kept on them. Twenty-nine (97%) were aware that the notes were available to them, the exception being a patient suffering from a confusional state. It was acknowledged that the ward team could choose to refuse access to an individual if they so wished, but this did not occur during the period of the study. All the patients on the non-access ward said they were aware that notes were kept on them. Most of these patients (90%) said that they never discussed what was written in the notes with the staff.

The 'access ward' specialized in forensic psychiatry and all the patients had committed serious offences. All but 2 suffered from psychotic mental illness, 24 from schizophrenia with paranoid ideation and 4 from major depressive illness. There was considerable variation within the group with regard to the degree of recovery. The majority (21) of patients on the 'non-access' ward suffered from neurotic conditions, depression being the commonest. The remainder (9) suffered from psychotic mental illness, 4 from schizophrenia and 5 from manic-depressive psychosis.

*Information of interest to patients (Table 1)*

The majority (80%) on both wards were particularly interested to read the notes in order to find out more about the staff view of their diagnosis and behaviour. One patient said she liked to know 'how the team assess you and reach their conclusions'. A patient who had not been offered access considered that reading the notes would 'give me an outside view of myself' and another thought that by refreshing her memory of how she was when she was admitted she would be able to 'see if I'm sane again'.

The staff views on social problems such as difficulties in relationships, employment and housing were of less interest. A minority believed that these matters were private and should not be recorded in the notes. The general issue of the staff view on their future was understandably of major concern, in particular the likely discharge date. All but 4 of the patients on the forensic unit said they would like to read about whether the staff thought they were dangerous or likely to commit an offence in the future. It was of interest that a few offender patients said they had no interest in reading about these particular issues as they considered them of no relevance to themselves.

*Table 1. Information of interest to patients*

| *Information category* | *Access (n=30)* | *Non-access (n=30)* | *Total n (%)* |
|---|---|---|---|
| Diagnosis | 25 | 26 | 51 (85) |
| Current mental state | 27 | 26 | 53 (88) |
| Drug treatment | 23 | 23 | 46 (77) |
| Problems in relationships | 21 | 22 | 43 (72) |
| Employment difficulties | 24 | 20 | 44 (73) |
| Financial difficulties | 20 | 15 | 35 (58) |
| Housing difficulties | 23 | 19 | 42 (70) |
| Future plans | 29 | 24 | 53 (88) |

Total number of patients=60

*The subjective effects of reading the notes (Table 2)*

There was a general consensus that while reading the notes might prove upsetting at times that it would not be appropriate to describe the practice as harmful. Patients often qualified such comments saying that even if it were, they would prefer to retain the option of deciding for themselves whether to read the notes or not.

With regard to specific feelings, 19 (65%) of the patients considered that they felt better about themselves through having access to notes. Six (21%) said they sometimes felt sad on reading the notes, 12 (41%) had felt anxious at times and 6 (21%) had felt bored. Eleven (38%) had experienced anger towards the staff on occasions, but all reported being able to acknowledge and discuss the feelings engendered. One paranoid patient described feeling angry when he had read nursing comments on his reaction to a relative's visit, but found that reading the comments enabled him to discuss the situation more openly with his keyworker. Ten patients (34%) considered that the staff always wrote the truth about them and 19 (65%) that they usually did.

Case history: Mr R was a 25-year-old man diagnosed as schizophrenic and admitted under Section 37 of the Mental Health Act (1983) following his setting several fires at his home. His mental state and self care had deteriorated over several months prior to admission.

He had experienced a disturbed childhood and attended a school for the maladjusted during his teens. He had been thought disordered on admission but was fully recovered when he made the following comments. He said reading the notes gave him a 'sense of security and authority' [2], helped him think about his problems and trust the nurses more. He also felt it important for him to know what was said in staff 'pow wows'. The authors were surprised that he said he had discovered he had schizophrenia through reading the notes. Although he was initially disturbed by this realization, in the longer term he had found it helpful to have gained an understanding of what this might mean for him. Access appeared to facilitate further discussion of information that would have been given verbally earlier during the admission.

The survey of patients' views indicated that the comments made in this case were typical of the whole. Twenty-two (73%) of patients on the access ward favoured access, the remaining 8 (27%) had no definite

*Table 2. Patient views on the effect of access*

| *Reported effect* | n | % |
|---|---|---|
| Better understanding of problems | 18 | 62 |
| Better able to discuss problems with staff | 25 | 86 |
| Able to put forward own views | 25 | 86 |
| Helpful in correcting errors | 25 | 86 |
| Greater involvement in treatment | 22 | 76 |

Total number of completed questionnaires=29

views on the subject. None regarded open access as undesirable. All the patients had read their notes at some time, 70% spontaneously and the remainder only when encouraged by staff.

On the non-access ward, 26 (87%) supported an open records policy, 2 (10%) said that it did not matter to them and 1 considered the practice undesirable. Several participants qualified their support of an open access policy by saying that while they favoured reading their own notes they had reservations about whether this would be appropriate for other people.

The majority of patients on both wards expressed curiosity 'to find out what is written about me'.

Patients on the non-access ward were asked if particular aims might be fulfilled through having routine access. Eighteen (60%) thought that access might enable them to discuss their problems more freely with staff, 17 (57%) that it might help them to understand their problems better and 20 (67%) that it would facilitate their being able to put forward their own views. One individual added that it might be useful for litigation.

## Discussion

There has been considerable debate as to whether a respect for individual rights requires that patients be given access to medical records. Westin[6] asks 'Is this anything the average patient cares about or is it an instance of self-appointed activists interfering with delicate professional relationships?' The findings of this study, suggest that most patients positively want the right to see their records. The principal reasons given by both groups for either wanting access or in support of continuing access were twofold. Most commonly it was believed that access would demystify the contents of the notes, and facilitate feedback and discussion with staff. There was remarkably little difference between the two groups even though their diagnostic characteristics differed in many ways. The vast majority wanted to learn more of the clinical details relating to them and the relationship of these to their future.

It has been suggested that caution should be exercised regarding patient access to psychiatric records, but apart from vague warnings that patients may be harmed, the reasoning in support of this advice is seldom elaborated. It can be postulated that concerns include that psychiatric patients are too disturbed to read their notes; that staff-patient relationships would be impaired especially where patients were prone to paranoid ideation and that granting access would place time consuming demands on staff. Our findings taken in conjunction with those of comparable studies[9,10,11] go some way to allay concern regarding these particular issues.

Most of the patients on the access wards suffered from serious mental illness, but it was our impression that all those who wished to read the notes did this appropriately and within the structured framework of daily reviews with the nurse keyworker. A keyworker system operated on the non-access ward but over half the patients considered that the feedback they received from staff would be enhanced if they were able to read notes. Both wards in this study were adequately staffed such that appropriate time was available for nurses to work with patients on an individual basis and it is possible that access to notes outside a personal communication framework could compound rather than ameliorate communication problems.

There was no indication from this study that access fuelled antagonism between patients and staff. Most patients thought they were better able to discuss their problems with staff, better able to put forward their own views and considered that access enabled them to correct errors. The sense of being involved in their own treatment is particularly significant in the light of the fact that the majority of the patients on the access ward were detained under the Mental Health Act. These effects taken together could be expected to inhibit the development of paranoid feelings. The effect on the patients of increased exposure to written descriptions of their inner experiences merits further study, but the patient's subjective experiences seem to be predominantly beneficial. Possible problems associated with access to information obtained from third parties may be of concern, but this topic was not addressed in this study.

Current trends in the nature of doctor-patient relationships indicate a change towards a less paternalistic relationship with the doctor placing more responsibility on the patient[14]. An element of paternalism may be appropriate in the treatment of certain psychiatric patients, but it is questionable as to whether this attitude should pervade areas where the value to patients remains unsubstantiated. This study lends no support to the view that patient access to records on a psychiatric ward would lead to time consuming demands, paranoia and deteriorating relationships. Rather it indicates that where access is incorporated into regular discussions of treatment and progress, the patients' views are favourable.

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## References

1 DHSS Circular HC (87) 14, Data Protection Act 1984; modified access to personal health information
2 Gillon R. Telling the truth and medical ethics. *Br Med J* 1985;**291**:1556-7
3 Gevers JKM. Issues in the accessibility and confidentiality of patient records. *Soc Sci Med* 1983;**17**:1181-90
4 DHSS Circular DA (85) 23, Data Protection Act - subject access to personal health data
5 Wilcox DP. Release of Medical Information to patients and insurance companies. *Texas Reports on Biology and Medicine* 1980;**76**(3):69-70
6 Westin A. Medical records: should patients have access? *Hastings Cent Rep* 1977;**7**(6):23-8
7 Shenkin B, Warner D. Giving the patient his medical record: a proposal to improve the system. *N Engl J Med* 1973;688-92
8 Sergeant H. Should psychiatric patients be granted access to their hospital records? *Lancet* 1986;ii:1322-5
9 Chamberlain G. Should patients read their own medical records? Editorial. *J R Soc Med* 1987;**80**:541-2
10 Stein EJ, Furedy RL, Simonton MJ, *et al.* Patient access to medical records on a psychiatric in-patient unit. *Am J Psychiat* 1979;**136**:327-9
11 Roth LH, Wolford J, Meisel A. Patient access to records. *Am J Psychiatry* 1980;**137**:592-5
12 Bird AP, Walji MTI. Our patients have access to their medical records. *Br Med J* 1986;**292**:595-6
13 Baldry M, Cheal C, Fisher B, *et al.* Giving patients their own records in general practice: experience of patients and staff. *Br Med J* 1986;**292**:596-8
14 Toom PD. Promoting prevention and patient autonomy: discussion paper 1987. *J R Soc Med* **80**:502-4

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